

...offering
**information &
inspiration**
to individuals with
disabilities and
their families
as they direct their
own supports and
services



Volume 3, Number 9
September 2005

Another View

Family Perspectives on Real Life Choices for Adults with Autism

by Leslie Long

Real Life Choices (RLC) holds the promise of flexible and person-centered services for individuals with developmental disabilities. It is a beacon of light for families struggling to keep their son or daughter at home for as long as they can, and in most cases, with no other options. When first asked whether self-directed services is what they wanted, there was a resounding 'yes' from many families.

*"I think things will be better
in the future with RLC,
because the agencies
will be ready.
We got a budget in June,
but there was
nothing to buy...
It wasn't like you had a
bunch of options to choose
from at one time."*

But how has Real Life Choices, as it is currently structured, *really* delivered for people with autism? That question is being discussed in the autism community as Real Life Choices is rolled out across the state. Parents of adults with autism, aspergers syndrome and related disabilities were interested in hearing what families using RLC had to say, so I asked them to share their thoughts and experience.

One parent says:

"Although Real Life Choices as it exists today is not a program that fits the needs of my son, my hope is, as the program matures, it would be an option. My initial impression was that the programs at all levels were initially surprised and somewhat unconvinced that the program did not have the necessary support structure or budget to effectively care for adults with autism. This fact is not surprising considering the lack of understanding of autism in the developmental disabilities system. Individuals with autism initially selected for RLC were selected based on faulty data derived from an inadequately designed intake instrument. The "Life Plans" developed after meeting with families, were once again based on a limited understanding of autism. Even as case workers worked past arbitrary deadlines, developing a relationship with families and a deeper appreciation for the 'real' needs of their clients, they were locked into an inflexible program with many limitations. So, what is the positive side of this self-directed model?

continues on page 2

Another View...

From the Cover

Parents are making their voices heard and needs known to DDD, and COSAC has offered to work with the Division to develop a better assessment tool and train case workers on the needs of adults with autism.

If Real Life Choices is one option, we can explore, expand and develop new programs depending on what we have learned. The idea of self-directed programs has energized families and given them hope. But like every other aspect of living with autism, it will take time, energy and advocacy to develop effective programs and secure funding."

Another parent shares her experiences:

"We didn't know when - or if - our son could get a traditional day program slot, so we went with Real Life Choices for Transition. We got our budget, but it really didn't seem to be enough for the structured environment that my son would need. For example, three days at a structured program would have used 75% of the budget, even though the program wasn't ready yet. I was working on two self-hires for physical activity and socialization, and met with an agency who was looking for someone who could take my son to volunteer opportunities, such as a local food pantry.

But last week I got a call from DDD. They said my son could get a slot at a day program that we liked right here in town. We said "YES!" This particular program seems flexible enough that we don't feel like we're giving up much by leaving Real Life Choices for Transition (we actually never spent any of our budget). My son will be starting in September.

I think things will be better in the future for RLC for my son, because the agencies will be ready. We got a budget in June, but there was nothing to buy. The program said they would not be ready to do RLC until October or November. Our local agencies were not offering anything. The self-hires had to do paperwork, blood tests and fingerprinting before they could start (I wound up using our money in the meantime). It wasn't like we had a bunch of options to choose from at one time.

Things needed to be done earlier. My son graduated less than two weeks after we got our budget, and one week after the

"...The idea of self-directed programs has energized families and given them hope. But like every other aspect of living with autism, it will take time, energy and advocacy to develop effective programs and secure funding..."

last planning meeting. For him, a structured program will always be best, but we didn't know when he could get into the one we wanted (funding uncertainty). If I had known that my son could have gotten the day program placement by the end of the summer, I would not have bothered. I think RLC for transition will work best if there are no programs that fit your circumstance. It gives you a lot more autonomy and flexibility, of course, but you have a lot more responsibilities to go with it."

Another parent reports on her experiences:

"Self-directed day services was a disaster for my son with autism. The budgeted amount from DDD was only \$16,000, which basically covers a "slot" in a generic workshop and transportation. Since this is just what we are trying to get out of (and what the self-directed system is hoping to eliminate) there seems to be no reason to take RLC at this point. My son also has unique safety and support needs - he is very vulnerable because of his communication limitations. Those needs were not addressed at all in his DDD budget. We truly feel "pinched" on all sides as it pertains to our son's supports. Housing is out - Real Life Choices fails someone like my son by funding him with an amount insufficient to support him in any fashion better than a traditional placement. Respite continues to come in at just over 4 hours a week. We are tired.

Unless the Division can figure out how to leverage funds, and work within the entire system in a more productive fashion I have no hope that things will improve for my son. We will continue to keep him safe, and beyond that, I just don't know."

Leslie Long is the Director of Adult Resources at COSAC, the New Jersey Center for Outreach and Services for the Autism Community. She can be reached at 609-883-8100. She would like to thank the parents who shared their experiences for this story.

Tips

for First Responders for

- ☐ Seniors
- ☐ People With Service Animals
- ☐ People With Mobility Impairments
- ☐ People Who Are Mentally Ill
- ☐ People Who Are Blind Or Visually Impaired
- ☐ People Who Are Deaf Or Hard Of Hearing
- ☐ People With Cognitive Disabilities

In An Emergency: What First Responders Need to Know

"Tips For First Responders" is an 11-page, color-coded, laminated 4.5 x 5.5-inch field guide that contains quick, easy-to-read information on how to assist persons with a wide range of disabilities, including Seniors, People with Service Animals, People with Mobility Challenges, People with Mental Illness, People who are Blind or Visually Impaired, People who are Deaf or Hard of Hearing, and People with Cognitive Disabilities.

The guide was designed for use by first responders and other emergency personnel who may be unfamiliar with how to interact with people with these and similar disabilities. The guide was developed as part of New Mexico's 9/11 emergency assessment process and includes the recommendations of a statewide task force on emergency preparedness for people with disabilities. The group was chaired by CDD staff, included all major disability groups in the state and produced recommendations that were incorporated into the state's revised all-hazards response plan. CDD staff have also been active in providing technical assistance to other states around issues of emergency preparedness and people with disabilities.

The tip sheets can be found at
www.cdd.unm.edu/products/TipsForFirstResponders.htm
 For more information, contact Tony Cahill at the CDD:
acahill@salud.unm.edu or (505) 272-2990.

READER INTEREST SURVEY:

Please tell us about the topics YOU would like to see in New Directions over the coming year:

- | | |
|---|---|
| <input type="radio"/> Hiring & Training Your Care Team | <input type="radio"/> Friendships and Relationships |
| <input type="radio"/> Managing Your Care Team | <input type="radio"/> Family Issues |
| <input type="radio"/> Health Care Issues | <input type="radio"/> Employment Issues |
| <input type="radio"/> Guardianship & Decision-making Issues | <input type="radio"/> Issues for people with mobility impairments |
| <input type="radio"/> Real Life Choices Updates from DDD | <input type="radio"/> Issues for people with social and behavior disabilities |
| <input type="radio"/> Fiscal Intermediary Updates and Info | <input type="radio"/> Issues for people with cognitive disabilities |
| <input type="radio"/> Budget Issues | |
| <input type="radio"/> Negotiating with DDD | |
| <input type="radio"/> Building Community Connections | |
| <input type="radio"/> Calendar of Events and Trainings | |

PLEASE ADD ME TO THE MAILING LIST TO RECIEVE NEW DIRECTIONS:

Name

Address

City

State/Zip

Send to:
 New Directions
 CCS Communications
 P.O. Box 384
 Hopewell, NJ 08525

September 2005

new directions

is produced by CCS Communications under a contract for the New Jersey Council on Developmental Disabilities.

The views and opinions do not necessarily reflect those of the editor, the Division of Developmental Disabilities or the Council, its staff or its volunteer members.

*Your letters and stories are welcome.
Authors of published stories will be paid \$100.*

Editor: Brenda Considine
CCS Communications
P.O. Box 384
Hopewell, NJ 08525

phone/fax: 609-466-0694
consid@comcast.net

"READY FOR TOMORROW'S JOBS TODAY:" National Disability Employment Awareness Month

October is National Disability Employment Awareness Month. The annual event, which began in 1945, recognizes the contributions of workers with disabilities. The theme for this year: "Workers with Disabilities: Ready for Tomorrow's Jobs Today," underscores the U.S. Department on Labor's national public awareness campaign which highlights the vital role that people with disabilities play in America's evolving workforce.

In cooperation with the national campaign, the New Jersey Division of Vocational Rehabilitation Services is sponsoring "**Disability Mentoring Day**" on **October 21**. Employees at New Jersey's Department of Labor will serve as mentors to job-seekers with disabilities and assist them in exploring.

For questions regarding ways to promote job opportunities for individuals with disabilities in high growth sectors of the economy, contact:

U.S. Department of Labor
www.dol.gov
Office of Disability Employment Policy
www.dol.gov/odep
(866) 4-USA-DOL • (866) ODEP-DOL
(609) 633-7365

New Jersey Department of Labor and Workforce Development
Division of Vocational Rehabilitation
www.wnjp.in.org
(609) 292-5987

new directions

New Jersey Developmental Disabilities Council
P.O. Box 700
Trenton, NJ 08625

FIRST CLASS U.S.
POSTAGE
PAID
Trenton, N.J. 086
PERMIT #21